**Addressing Choices & Preferences of Individuals with Dementia and Swallowing Difficulties**

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Swallowing difficulties or dysphagia, become more prevalent with increased age, (1) ranging from 7% to 22% in the general population and dramatically rising to nearly 60% in adults who reside in long-term care facilities. All types of dementia may be associated with dysphagia, which is a growing concern due the associated health risks of malnutrition, dehydration, weight loss, functional decline, and a general decrease in quality of life. (2)

Eating, drinking and swallowing (EDS) requires cognitive awareness, visual recognition of food/drink, physiologic response, motor planning and execution of patterned sensorimotor responses. (3) With all the related behaviours that go with eating and drinking, there is much more involved than just the act of swallowing. Individuals with dementia, who experience deficits in attention, initiation, orientation, recognition, executive function, decision-making and apraxia will subsequently experience difficulties with eating and drinking.

The physiological role of the swallow is to prepare the bolus and ensure its passage from the mouth to the stomach, without compromising the airway, however, swallow physiology alters with advancing age and disease. The reductions in muscle mass and connective tissue elasticity result in loss of strength (4) and range of motion (5) affecting oral and pharyngeal structures involved in the process of swallowing.

In the early stages of Alzheimer's dementia, individuals may not have the focus, attention and sensory awareness to chew down and propel the food bolus. (1) The entire process of EDS is slower with an increased number of swallows, leading to a delay in oral preparation of the food bolus. Over time, these subtle but additive changes can contribute to increased frequency of residue penetrating into the upper airway, in addition to post-swallow residue in the pharynx. (5)

The cumulative cognitive and physiological changes in older adults with dementia and EDS difficulties, can impact on the development of aspiration pneumonia which has been extrapolated from the literature, as the most common cause of death amongst this population group. (6). The development of aspiration pneumonia may occur due to a combination of dysphagia and contributory factors such as poor oral hygiene, being dependent on others for assistance when eating and drinking, and high support needs for positioning during mealtimes (7; 8). There is, however, no direct relationship between dysphagia and aspiration but rather several factors that can contribute to a number of risks. Dysphagia is one of the contributing factors with aspiration being one of the risks. Other risks can include, choking, malnutrition, dehydration, distress and social isolation.

The decision-making around eating and drinking, taking cognisance of the resultant risks, is therefore complex, involving the assessment of nutritional options and recommendations, weighing up benefits and risks, prognosis and capacity to consent. The individual living with dementia is central to the shared decision-making process.

As ethical dilemmas cloud decision-making it is about how the decision-making process around choices and nutritional planning can be structured so that it is explicit against the greyness of ethical uncertainties. For individuals with advanced dementia, the spotlight is on quality of life which should warrant the dignity and time to establish the individuals wishes, recognise the risks and problem-solve how best to address these risks. The 'how' is the catalyst to galvanising the decision-making process from grey to black and white which can only be achieved through collaboration with the multidisciplinary team.

A referral to the speech and language therapist will facilitate an individualised assessment with possible food/fluid modification and recommendations on what appears most palatable and comfortable. Discussions with the individual and those closest to them should occur about what is important in relation to eating and drinking for the individual themselves. Food preferences, mealtime routines, cultural, religious and spiritual beliefs associated with food are essential to the assessment but also to understanding the psychosocial impact of dysphagia and its associated interventions on a person's wellbeing.

A person's cultural knowledge and values create unique beliefs and perceptions that shape their understanding of health and illness, the ways that they access healthcare services, the actions they take to seek support, their expectations of care, and response to recommendations. (9) These are intrinsic components to be aware of as clinicians to help facilitate accessibility and responsiveness to culturally diverse communities living with dementia.

Liaison with the dietitian is pertinent to optimising nutritional intake whilst involvement of the physiotherapist is necessary for not only maximising the individual's position and posture but also when planning respiratory care jointly with the medical teams. Consultation with the nursing staff is paramount in acknowledging and minimising risks with scrupulous mouth care whilst supporting the individual to follow eating and drinking recommendations as much as is possible. Integral to safe medicines administration is engaging the pharmacist or medical team member to review medication formulation, which is frequently overlooked in practice. Medical teams might undertake an assessment to establish the individuals decision-making capacity or liaise with SLT to carry this out but are rigorously involved in the documentations of discussions with completion of anticipatory care plans/advanced directives, when required.

Taking this approach means the risks of aspiration, dehydration and malnutrition in individuals with dementia and EDS difficulties will be reduced by adhering to the 5 fundamental Ms; **multidisciplinary** care, **mealtime** preparation, **maximising** positioning, **mouthcare** and **medication** review (10).

Ultimately, health and care systems globally should be harnessing a person-centred approach by empowering individuals to make decisions about their care in anticipation of a deterioration of swallowing, at the time of a diagnosis of dementia. At whatever stage decisions are made, it is cardinal that these decisions are captured within anticipatory care plans, advance care directives and communicated across primary and secondary health care services. Suggestions on a multidisciplinary framework for shared decision-making can be found within the RCSLT multi-professional guidance on eating and drinking with acknowledged risks. (11) The guidance aims to clarify the assessment, decision-making and documentation processes required in order to achieve person-centred, multidisciplinary and multiagency care planning with clear methods of review for individuals.

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